

breaking ground

NUMBER 101

APRIL 2020



BE COUNTED.
BE HEARD.



Council on
Developmental Disabilities

Dear readers,

This is a big year in the disability community.

- Councils on Developmental Disabilities celebrate our 50th anniversary.
- The Americans with Disabilities Act celebrates its 30th anniversary.
- State Vocational Rehabilitation programs, which provide support for people with disabilities to work, celebrate their 100th anniversary.

Aside from these big milestones, this year offers important chances for people with disabilities to **be counted and be heard**. In this issue of Breaking Ground, you'll read about the census and why it's important for people with disabilities to take part. You'll also read about work we're helping fund to make sure voting places are accessible so people with disabilities can be heard in this year's elections – and all elections to come.

We know that a quarter of the U.S. population has some type of disability. In Tennessee, about 108,000 people have developmental disabilities. Every one of us is connected to disability in some way, either personally or through someone we love.

The anniversaries we celebrate this year outline an arc of real change for people with disabilities. As a Council, we are looking to the next 50 years. We know that change happens when our community works together to be sure the voices of people with disabilities are present and heard: in every classroom, every community, and every room where decisions are made that affect their lives.

Join us this year. Be counted. Be heard. Together, we are shaping the future for people with disabilities in Tennessee.

Sincerely,

Wanda Willis
Executive Director



Table of Contents

- 4 Teaching Empathy
- 6 My Path Back to Career after Traumatic Brain Injury
- 7 Tennessee Deaf Mentor Program
- 10 Voting is Power
- 12 Your Chance to Be Counted
- 13 Council Member View: Disability Day on the Hill
- 14 Tikkun Olam Makers: Vanderbilt
- 17 Meet our New Director of Leadership Development
- 18 TN's Early Intervention System: What You Need to Know

On the Cover: Tyler Samuel, professional vocalist and a regular in the Nashville theater scene, is an advocate for the arts and for the Deafblind community. She is the daughter of new staff member Cathlyn Smith.

Learn more about the Tennessee Council on Developmental Disabilities.

615.532.6615 | www.tn.gov/cdd | www.facebook.com/TNCouncilonDD | Tnddc@tn.gov
 Subscriptions to Breaking Ground are free and available through the Council website. Visit tn.gov/cdd to subscribe or contact us by phone or email with subscription updates or requests, and please include name and mailing or email address.

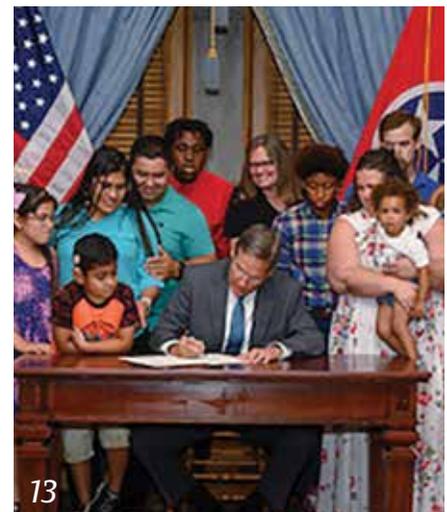
This project was supported in part by grant number 1901TNSCDD, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.



4



10



13



14



Tennessee Council on Developmental Disabilities, Reauthorization No. 344067, March 2020, 12,000 copies. This public document was promulgated at a cost of \$1.69 per copy.

Teaching Empathy

Helping My Daughter's Classmates Learn about Disability

By Alison Bynum, Council on Developmental Disabilities, Mid-Cumberland Development District

My daughter Charlotte is 11 years old. She loves riding horses, the movie *Frozen*, and going to church. She doesn't communicate by speaking, and while she is learning to use an eye-gaze computer, she currently uses facial expressions to let us know how she is feeling.

Her multiple disabilities and complex medical needs are very different from the needs of most of her peers at school. Charlotte has been enrolled in public school since she turned three. Her first experience was an integrated classroom, full of students with special education needs and peer models who did not have special education needs. When she transitioned into elementary school, her time around peers without disabili-

ties decreased dramatically. She now spends most of her day in the self-contained special education classroom, joining the students without disabilities a few times each day.



Alison Bynum

I am not here to debate placement for every child, as that is a more complex topic. From what I saw, however, during Charlotte's inclusion in the general education setting, I sensed a lack of connection between my daughter and her peers. She popped in and out of their classroom, but did not seem to be part of the group. It wasn't anyone's fault. She was present. She was THERE.

Inclusion is not just about being near your peers. A seat at the table is just a seat at the table if no one talks to you. We have all had that experience of being present but not being a

part. If only the other students knew all the things about Charlotte that she was not able to communicate without support, maybe things could be different. I wondered: What if I could just talk to them?

I approached Charlotte's fourth grade teacher with an idea for a training at the beginning of the school year to help Charlotte's classmates learn about her and her disability. I believed teaching the students about my daughter and her needs openly and honestly would promote empathy, or compassion and understanding. They would think about how it felt to be Charlotte.

The teacher was more than willing for me to come and spend 20 minutes with the class, leading group discussion on being alike and different, and what it means to be a team. Then we transitioned into empathy exercises to show specific physical challenges for their classmate.

We covered topics such as how her arms and wrists are drawn tight to her chest and had them role play this. We practiced not being able to extend your arms to pick up a lollipop in front of you, and how a partner could support you to achieve your goal of reaching the candy.

We talked about how muscles also control swallowing. We showed the suction machine that Charlotte uses so that it would not be alarming if it came on during their time



Charlotte Bynum's teacher interacts with her as they read together with her class.



Charlotte Bynum enjoys story time with her class.

together. We discussed: if swallowing isn't an option, where does drool go? The students understood why Charlotte wears a scarf to protect her clothing and skin from getting wet.

To end our time together, I opened it up for questions and drove home the point: asking questions TO LEARN is always okay. Asking questions to be mean is NEVER okay.

This small investment of time in the beginning of the school year opened the door to many positive experiences for Charlotte over the year. Her friends were more engaged with her each day at school. A friend even became so concerned about there not being a way for Charlotte to use the playground that she wrote a letter to her principal asking for a new piece of inclusive playground equipment. Advocacy was an outcome I did not expect, but it was even better than I had hoped.

At the beginning of fifth grade, I made the same request of Charlotte's new teacher: an opportunity to do an empathy training. There were a few students who remembered the exercise from the previous year, and they became my assistants. The students asked more in-depth questions.

The level of support and friend-

ship the students have offered has increased with their maturity and growth. This year, Charlotte's peers have worked with her as communication partners on her eye-gaze device. They have read books to her and even supported her by working hand over hand to complete tasks. On field trips, they have chosen to sit in areas that her wheelchair could also access and have brought materials to her so that she could touch and see.

The students asked their teacher if they could plan a surprise birthday party for Charlotte, because her birthday was happening over fall break. They brought items from home and assembled them as decorations. They wrote encouraging notes to Charlotte and put them in a gift bag, and they donated some of their "Bolt Bucks" earned through their own good behavior so that she could shop in the school store and choose a gift for herself! The smile on her face when she saw what they had done was one of sincere love and appreciation.

Through empathy trainings, my daughter enjoys being supported by her peers and has increased her self-worth and self-confidence. She engages in class more and

The concept of empathy training about a student can be replicated in many settings by using four steps.

1. Discussion Questions:
 - a. What does it mean to be alike/different?
 - b. What does the word "disability" mean to you?
 - c. What does it mean to be on a team?
2. Student-Specific Education: Share how the student with a disability is alike to and different from their peers without disabilities. Share age-appropriate information about the student's disabilities with permission.
3. Empathy Exercise: Choose some role-playing empathy exercises that relate to the student's disabilities, as a way to build understanding.
4. Questions & Answers: Allow students to ask questions until they understand. Teach how to ask respectful questions.

contributes to her community. She is more awake and alert and even has improved school attendance during the last two school years. I hope sharing this simple exercise will help other students experience these same kinds of positive results, build empathy and understanding in schools, and more!

Alison Bynum is a freelance photographer and marketing consultant based in Smyrna. She serves on the Family Advisory Council for Monroe Carell, Jr. Children's Hospital at Vanderbilt, and she and her husband, Brad, are active members of LifePoint Church, Stewarts Creek Campus. ■

My Path Back to Career after Traumatic Brain Injury

By Drew Gilmer

Hello, my name is Drew Gilmer. My legal name is William Andrews Gilmer, but I've always used the name Drew. I am 49 years old and have lived in Middle Tennessee for most of my life.

The majority of my work career was spent at BMI, or Broadcast Music Incorporated. I truly enjoyed my time with BMI. I temporarily moved to New York City to work in the NY office. I lived in New York for nine years and then returned to Nashville in 2012.

I had only been back for a few weeks when I got in a bad car accident. Although I survived, this incident drastically changed my life. I developed brain trauma from the accident. It doesn't really affect me, but it slowed my processing speed. Thus, I was unable to handle the large number of phone calls received at BMI.



Author Drew Gilmer poses at the ASCAP offices

Eventually, I left BMI to pursue a new career. I was hesitant, because I had been with BMI for more than 20 years. Unfortunately, I could not keep a job there with my slow processing speed. It was an uneasy feeling, but I really had no other options.

The first job I obtained was at Publix grocery store. I was familiar with grocery stores from a past job bagging items, so I worked in customer service. I quickly learned that Publix doesn't have a cleaning service. Instead, all the cleaning is performed by the employees, especially in the customer service department. I could handle all my job duties, but the cleaning needs frustrated me.

I ended up leaving Publix and got a job at the Downtown YMCA. It was interesting working for the YMCA, because I used to go there with my father. I really enjoyed working for the YMCA, but my brain issue was causing me to be periodically late, and I eventually was fired.

I knew a woman who works for New Visions (a vocational services agency), and she was helping me to locate another job. She mentioned a "farm" for me to explore. I thought about it and decided to check it out. It's called "Cul2vate" and is located in the Crieve Hall area, close to Overton High School.

We visited the site, and I was very impressed. It was a six-month program, and I decided it was a great opportunity. I don't proclaim to be a

farmer, but I enjoyed growing supplies for people. I was finally feeling a purpose in my work. It's very gratifying to help people in this manner.

One aspect I truly respected about Cul2vate was that it was faith-based. We had meetings in the morning and discussed lessons from the Bible. This gave me a strong feeling of pride and desire to work harder. I'm still friends with the owners and plan to volunteer in the near future.

I was finally feeling positive about my work career and decided to take a few weeks off before a new job hunt. Most of my experience came from BMI, which is a Performing Rights Organization or PRO. Every country in the world has one PRO. In the U.S., however, there are three. The main two are BMI and ASCAP. I was done with BMI, but I had a desire to work at ASCAP.

I eventually got an opportunity to interview with someone at ASCAP. I was extremely excited because this was the one place I had related experience. I was motivated and completely happy at my interview. Fortunately, I was familiar with all the language from my BMI career.

I have really enjoyed my days at ASCAP. It's essentially the same type of business as BMI, so everything is familiar. On top of that, I no longer answer phones, so I'm absolutely satisfied. ■

Tennessee Deaf Mentor Program

By Briella Diaz, Coordinator of the Deaf Mentor Program, Tennessee Schools for the Deaf

Imagine: You are a parent and have just given birth to a Deaf baby. This baby is statistically likely to be the first Deaf person you have ever met.

You are swarmed with dozens of medical professionals telling you how best to raise your child. You are swamped with information overload.

It can be a lot of pressure to make the best decisions for yourself and your family when you are still unsure what the future will hold for someone who is Deaf. This is where the Deaf Mentor Program comes in!

This new program was created by Tennessee law in 2019, and is offered through Tennessee Schools for the Deaf. It comes after many years of work by advocates and Deaf organizations.

The program is now in the pilot stage. Its main purpose is to empower parents of Deaf children from the ages of zero to five to make the most informed decisions on how to raise their child and how the family chooses to communicate. It is also a way for hearing parents to meet successful, well-adjusted Deaf adults, and for the Deaf child to have a Deaf role model in their lives from an early age.

The program provides a Parent Advisor, who comes into the home for hourly visits once a week to provide support and healing for the family. The Parent Advisor is a trained hearing professional who is well-versed on Deafness, both medically and culturally. The Parent Advisor also provides listening and spoken language support for the child and family, when desired.



Advocates surround Governor Bill Lee as he signs the Deaf Mentor Pilot Project bill into law in 2019.

A Deaf Mentor will also come to the home on a weekly basis to provide perspective and healing for the family. The Deaf Mentor is a trained Deaf professional who is competent in American Sign Language (ASL) and Deaf culture. When desired, the Deaf Mentor will provide ASL lessons and teach the family how to best raise a Deaf person, based on their own personal experiences of being Deaf.

The goal of the Deaf Mentor Program is that by the end of the year, families will feel comfortable using both ASL and English in their households. Another goal is that families will feel confident and empowered to advocate and to make decisions that are best for their Deaf child.

Because this program is in the pilot stage, the framework is still being put into place. We are currently working with 13 children from 11 families in the greater Knoxville, Nashville, and Chattanooga areas.

We have hired contract Deaf Mentor employees Sharon Bryant and Sydney Ackers, and a Deaf Men-

tor Coordinator, Briella Diaz, to provide services to those families. We also have Tracy Duncan and Alisa Weeks contributing to the program as Parent Advisors. All professionals have been trained under "SKI*HI," a certified national Deaf Mentor training program that provides a curriculum for the Tennessee Schools for the Deaf to use.

It is our goal to expand this program so we can serve more families in the state and provide support to more Deaf children and their respective families. Any further questions about this program can be directed to the Deaf Mentor Program Coordinator, Briella Diaz, at b.diaz@tsdeaf.org.

Briella Diaz was born Deaf to a large Deaf family. She was raised in Utah and recently moved to Knoxville, Tennessee. She has a degree in bilingual outreach from Gallaudet University and is passionate about early intervention and ASL. She enjoys listening to music and translating English lyrics into ASL. She looks forward to getting to know Tennessee in the years to come! ■

Voting is Power

By Brian Keller, Public Policy and Voting Attorney at Disability Rights Tennessee

One of the most important ways we participate in our community is by voting. Sharing opinions and information on the Internet is easier and takes less time, but voting is much more powerful. Our votes choose the people who make important decisions that impact our lives every day. And when we meet with them in person, our record of voting shows our legislators we mean

GET INVOLVED

Make sure you are registered to vote or have your voter registration up-to-date. You can register to vote online at <https://ovr.govote.tn.gov/>. And always remember to vote!

business. If people with disabilities don't vote, then our unique needs and perspectives may not be taken into consideration. The Council on Developmental Disabilities helped fund the work we're doing to make sure the voices of people with disabilities are heard through voting.

Access is Key

If our poll sites are not accessible, voting is difficult. Getting in and out of a polling place, knowing what to expect when you go to vote, and receiving the help you need are critical in order to vote. At Disability Rights Tennessee (DRT), we work hard to ensure that poll sites are accessible.

Poll sites are temporary spaces. They pop up on Election Day and are gone that night. Often poll sites use spaces typically used for different things, like school gyms, hallways of public buildings, or church meeting rooms. These shared spaces aren't designed to be poll sites. Sometimes their usual use doesn't require them to meet Americans with Disabilities Act (ADA) standards. So, ensuring physical access to a poll site takes special time and attention by each county's election commission.

Voters have a broad range of needs when it comes to the voting process. Anyone who needs any accommodation to vote has a right



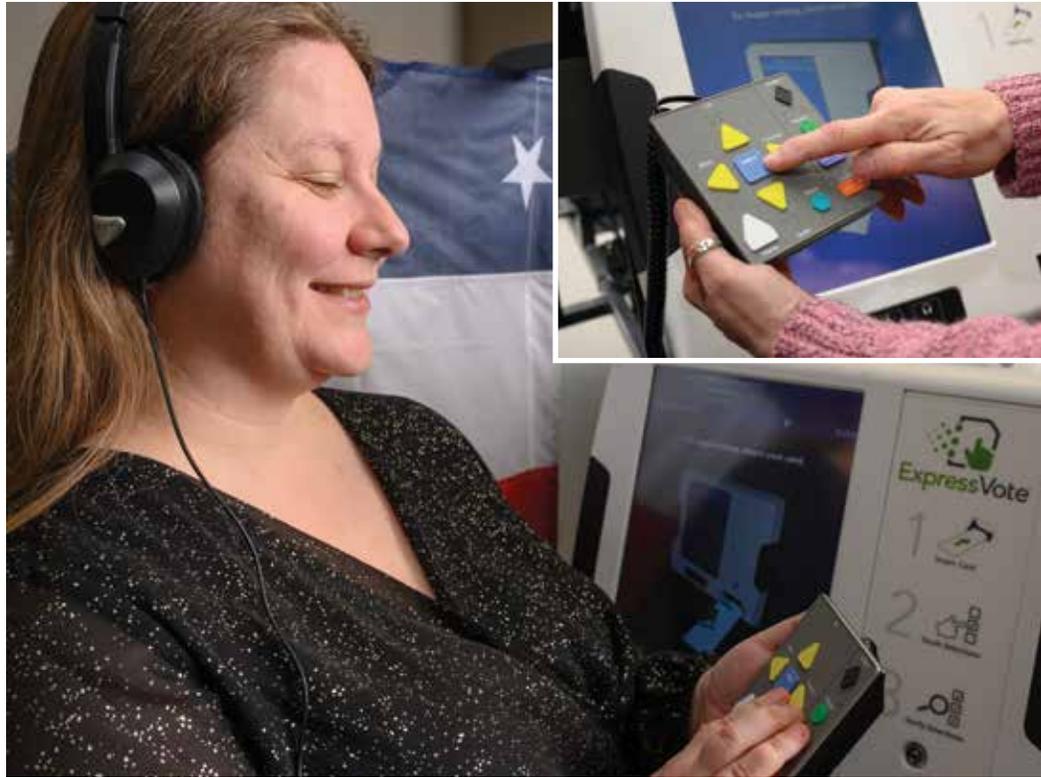
GET INVOLVED

Request a Voter Registration in a Box by emailing Brian Keller at briank@disabilityrightstn.org.

to ask for and get the help they need. For example, a person may need a sheet magnifier to read the ballot clearly. A person with a mobility barrier may need someone to help them enter their vote in the machine. For a poll site to be accessible, poll workers must understand how to meet the diverse needs of people with disabilities in their setting.

Making Change

Before elections even begin, DRT is working to make voting accessible for all Tennesseans. Together with the Secretary of State, we educate voters about their rights to accessible voting. We train poll site workers about meeting voters' needs. When you visit your polling site on Election Day, you will most likely see our Voter Bill of Rights poster. You



might even see our "Helping Tennessee Vote" guide for poll workers sitting out for reference.

DRT also helps with voter registration with our Voter Registration

in a Box program. This program provides all materials and resources you need to host your own voter registration event in one convenient spot. The box has everything from



GET INVOLVED

Share DRT's Voter Hotline in your community. Consider contacting a local newspaper or radio station or sharing it in Facebook groups.

information about how to find an accessible venue and promote your event to the materials to support someone in registering to vote.

Voter Registration Boxes include:

- voter registration forms
- postage
- event fliers
- event stickers
- social media tips and sample posts
- planning guide
- educational resources
- return postage

And, if you have questions, DRT staff is available to help you!

On Election Day, DRT hosts a Voter Hotline. If you or someone you know has an issue accessing your poll site or voting on Election Day, you can call 1-800-342-1660 to report it. DRT works with the caller in real time to resolve the issue.

DRT also does poll site surveys on Election Day to make sure voting locations are accessible. DRT staff visit poll sites and look at whether they are accessible. After the election is over, we share what we found with the state and the county so they can try to fix any problems we found.

This year, we're excited to also have the help of volunteers to conduct poll site surveys. After a



one-hour online training, volunteers simply download our electronic poll site survey onto their iOS or Android device. Then, on Election Day, they visit a poll site or several poll sites, enter the data gathered, and help DRT keep voting accessible.

BE AN INFORMED VOTER!

More voting information:

- Disability Rights TN Voting Resources page - disabilityrightstn.org/resources/voting
- Self Advocates Becoming Empowered (SABE) GoVoter project - sabeusa.org/govoter
- Autistic Self Advocacy Network Voting Toolkit (ASAN) - Easy Read and plain language versions - autisticadvocacy.org/policy/toolkits/voting
- American Association of People with Disabilities (AAPD) R.E.V.U.P. campaign - aapd.com/advocacy/voting

Tennessee disability policy issues:

- TN Council on Developmental Disabilities weekly policy e-news - tn.gov/cdd
- Disability Rights TN Policy Watch e-news - disabilityrightstn.org
- The Arc Tennessee - thearctn.org
- TN Disability Coalition and Disability Day on the Hill - tndisability.org
- TennesseeWorks blog - tennesseeworks.org/blog

National disability policy issues:

- The Arc U.S. - thearc.org/
- Association of University Centers on Disabilities - aucd.org
- "Tuesdays with Liz" YouTube series
- Autistic Self Advocacy Network - autisticadvocacy.org/policy
- Self Advocates Becoming Empowered - sabeusa.org
- American Association of People with Disabilities - aapd.com
- National Disability Rights Network - ndrn.org
- National Association of Councils on Developmental Disabilities - nacdd.org
- OneVoteNow.org





Better Together

DRT works hard to increase voting accessibility so all Tennesseans are able to vote. When we all work together, we can make huge change. Let's help every Tennessean have their voice heard!

Brian Keller is the Public Policy and Voting Attorney at Disability Rights Tennessee. He focuses on following legislation and regulation through the process and educating policymakers on the impact proposed legislation would have on Tennesseans with disabilities. He also works with state and county election officials to ensure the election process is accessible for all voters. Brian graduated from Belmont University College of Law in 2016, where he served as president of the health law society. A native of Fayetteville, Arkansas, he lives in Nashville with his wife and puppy. ■



PERSONAL PERSPECTIVES: Why Voting Matters

Two members of the Tennessee Council on Developmental Disabilities give their thoughts about why voting matters for people with disabilities.

Q: Why is voting important for people with disabilities and their families?

Ryan Durham, Council Vice Chair, South Central District: "Voting is the very foundation of our democratic process. It is important for people with disabilities and their families for the same reasons it is important for the rest of Americans. Voting is the most crucial and direct role that the vast majority of our citizenry can play in governance. Clearly, voters carry more weight with elected officials than non-voters. So, it correlates that demographic populations and groups of Americans who are known voters have more access to and influence over the political process. If circles formed by people with disabilities and their families along with other advocates are known commodities on election day—in other words, we get out and vote—our messages will ring loud on election day."

Linda Monterroso, Member, Memphis Delta District: "Voting gives people a voice. If you are passionate about something that affects you or those you love, whether a new law or a change, it's important for you to support it and push for its success."

Q: What would you say to someone who thinks their vote doesn't matter?

Ryan: "Contending that 'your vote does not matter' is the same thing

as saying 'you don't matter.' Neither is true."

Linda: "If many people believe their vote doesn't matter, this can add up to many votes missed. This can mean the difference between one person or law being elected or passed. Voting is a privilege that many people – even many living in this country – do not have. We must make our voices heard."

Q: Why do you think some Tennesseans with disabilities may not vote?

Ryan: "Logistics sometimes present difficulties. Even with the advances of early voting and other accessibility features with that process, sometimes it's just hard to get to the polling place. Add to that the general malaise of voter apathy, and it's easy for Tennesseans with disabilities to think voting is not worth their time and effort. That's unfortunate, because very little is more important than voting to express your view on how our state and country operate."

Linda: "There could be a number of reasons. Some may be accessibility, lack of transportation, or the need for a companion to go with them. Others may feel they are not sure of the issues and how that may affect them in a positive or negative way. Whatever the reason, it's important to come together to offer support and encourage one another to vote."



Your Chance to Be Counted

Why the Census Matters

By Jolene Sharp, Chief Public Information Officer, Tennessee Council on Developmental Disabilities

Every 10 years, the United States counts every person living in our country through a census. This year, 2020, is time for a new census. The census affects many key things:

- How much money states get for Medicaid (TennCare), housing programs, food help, and schools. This includes funding for special education, Medicaid disability supports, housing help for people with disabilities, employment supports through Vocational Rehabilitation, and many other disability services.
- How many seats in Congress our state gets.
- Where lines are drawn for school and voting districts.
- How tax money is shared with cities and counties, for things like hospitals, roads, fire departments, and other important services.
- How much money state councils on developmental disabilities get. (That's us and our sister councils in other states!)

Tennessee Governor Bill Lee wants citizens to know how important the census is for our state. "We need your help to get an accurate count," Governor Lee said in a video announcement. "The census is a once-in-a-decade process of gathering information from households across the country. It's completely confidential and critical to making sure our hard-earned taxpayer dollars come right back into Tennessee."

If you don't take part in the census, you will not be included in the count of how many people live in your community and in our state. That means less funding for important disability and community services.

People with disabilities can be under-counted in the census for many reasons. These reasons include:

- accessibility issues
- lack of access to computers and internet
- higher rates of homelessness, and
- fears about how answering census questions could affect disability benefits

When will the census happen?

The census process begins in March. You have likely received a form in the mail with directions on several ways to complete the census. You will be asked to fill out the census by April 1.

The U.S. Census Bureau will share

the new census data with the public in November 2020.

How do I get counted in the census?

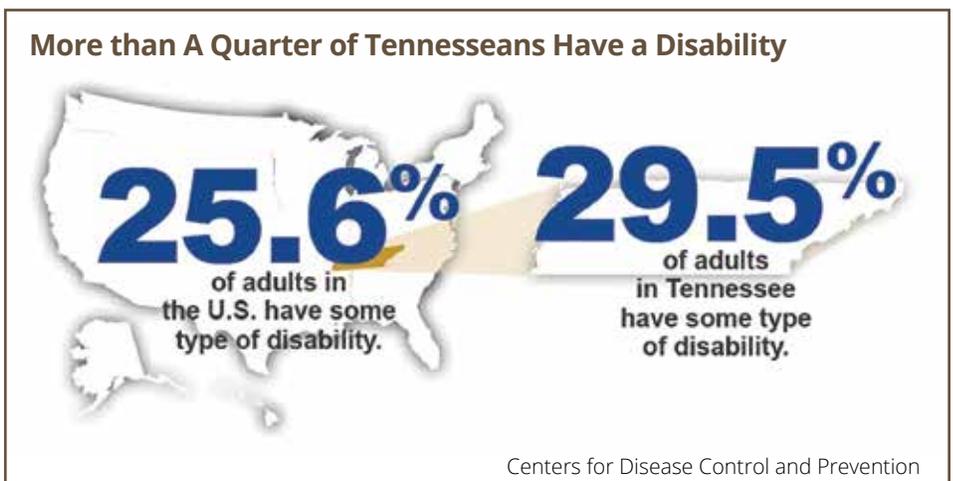
Only one person in each home should fill out the census for everyone living there. If you live with others, you can talk about who will fill out the census.

There are three ways you can take part in the census on your own:

- Online through an accessible website 2020census.gov
- On the phone, with census workers who speak more than 12 languages, and with Deaf-friendly services
- A survey sent to you by mail

You can ask for help filling out the census, from someone you know or from a census worker. If you don't have a computer or internet but want to fill out the form online, you can use your local library.

Continued on page 17



Council Member View

Disability Day on the Hill

By Sarah Cripps, Member of the Council on Developmental Disabilities, Upper Cumberland District

In the past, government has been content to keep those of us with disabilities at the edges of society. After attending Disability Day on the Hill at our State Capitol on February 4, I am convinced that such old ideas have been laid to rest once and for all.

As a newer member of the Tennessee Council on Developmental Disabilities – my term began in September 2019 – I had never attended such an event. A diverse group of Tennesseans attended the 2020 Disability Day on the Hill. This included people with disabilities, family members of those with disabilities, and disability rights advocates. In fact, this was the best-attended Disability Day on the Hill to date.

The morning session and panel discussion were held in our historic Old Supreme Court Chambers in the Capitol. Governor Bill Lee spoke and, by his presence and through his remarks, showed his commitment to improving the lives of all disabled Tennesseans.

A panel discussion gave attendees the chance to hear personally from members of the executive branch who oversee disability services across our state. These include leaders from the Commission on Aging and Disability, the Department of Education, the Department of Intellectual and Developmental Disabilities (DIDD), the Department of Labor and Workforce Develop-



Council members and staff gathered for a photo after the opening program.

ment, the Department of Human Services Vocational Rehabilitation, the Bureau of TennCare, and the Department of Mental Health and Substance Abuse Services.

Each panelist shared news about current programs and services as well as new programs at each agency. For example, we learned that the Tennessee Early Intervention System (TEIS) will no longer be under the Department of Education, but will now be under DIDD. *(Editor's note: For more information on that change, see page 18)*

The Council on Developmental Disabilities was well-represented on this panel by Council Member Clancey Hopper of the Mid-Cumberland Region.

Another highlight of the day was listening to comments from both Senator Becky Massey and Representative Sam Whitson about their work on disability issues, such as the passage of the Katie Beckett Waiver.

The Disability Coalition provided lunch, and many of us used this time to network informally.

During the afternoon, members of the Council met with their state representatives and senators. We shared our stories and discussed issues that matter to us all. That might be a lack of employment opportunities, improving voters' access to polling locations, the need for accessible transportation, or the need for adult changing tables.

Continued on page 19

Tikkun Olam Makers: Vanderbilt

Repairing the World

By Blake Hanan

Disability affects people across the world regardless of race, religion, or economic status. The current system for solving the challenges people with disabilities face is driven mainly by large, corporate medical companies. It is often expensive, difficult, and only applies to the mass market.

Not only does this drag down the innovative nature of this emerging market, it leaves millions of people without options. As a group of students at Vanderbilt University in Nashville, Tennessee, we are working to solve this problem.

Our student organization is called Tikkun Olam Makers: Vanderbilt. Our goal is to overcome cost barriers and red tape in the assistive technology market. We are bringing the ideas of the global nonprofit organization Tikkun Olam Makers (TOM) to the Vanderbilt and Nashville communities.

The idea is that we group together teams of “makers” and “need-knowers” for a 72-hour Make-a-thon. During the event, we develop assis-



Tikkun Olam makers and need-knowers pose together.

tive technology for specific challenges these need-knowers are facing.

A maker is anyone with engineering, designing, hacking, or advanced technical skills. A need-knower could be a person with a disability, a caretaker, or a professional in the field, such as a special education teacher or an occupational therapist.

The need-knowers are placed on a team with anywhere from two to 12 makers, depending on the project. The goal is to promote human-centered design during the 72-hour weekend. We try to target disabilities that are:

- not common enough to support a business model that would create a solution, or
- for which the current assistive technology is too expensive for most people.

The Make-a-thon itself uses what

we call the “Hacker Approach,” which is an improved – not necessarily perfect – solution that is open in nature. The products made during the weekend are created through a multi-step process that increases the quality of the solution with each step.

Designs made during the TOM Make-a-thon are later uploaded to an open source database that anyone worldwide can use and improve upon or develop themselves. This is where our goal moves past innovation and into providing affordable assistive technology globally.

In 2016, we began working hard to create the first TOM event, with the larger goal of building an ongoing TOM community at Vanderbilt and in Nashville. We looked to local companies and individuals for sponsorships and fundraising. We looked to the Vanderbilt and Nashville commu-



Team Abigail worked on a walker that brakes when a barrier is detected.

nity for recruitment of makers and need-knowers, through students and professionals in these fields.

After a year-and-a-half of planning, recruiting, and fundraising, we finally got the project off the ground in early 2018. In January, we hosted our first successful TOM: Vanderbilt Make-a-thon with seven teams, helping seven need-knowers. There was a range of projects, from purely computer science and coding projects to purely mechanical building projects, and some that combined both.

For instance, Eli was a four-year-old boy with cerebral palsy. His challenge was an extremely expensive wheelchair that would continually need expensive adaptations to accommodate his growing body. Team Eli worked directly with Eli and his parents to develop a wheelchair prototype that did almost all of the same things as Eli's original wheelchair, but for less than \$100. They also did a side project of programming a joystick so that he could control his favorite drone on his own from the seat of his wheelchair.

We were so impressed with the passion and determination the Nashville community brought to these projects that the next year, we expanded operations. In January of 2019, we held our second successful TOM Make-a-thon, hosting 13 teams.



Team Eli designed a highly-specialized wheelchair for a fraction of the cost, and added a joystick control for his favorite drone.

These projects had an even wider range of challenges, and broader skills needed to work on those challenges. There were iPhone/iPad apps created to help a classroom of children with autism. One team created a leg barrier and ball holder on a rugby wheelchair for an amateur rugby player. Another team made a sensor and braking system on a little girl's walker for when she couldn't see the barriers in front of her. There was even an off-road wheelchair created so a boy could go hiking with his family.

These are just a few examples of the designs created by Nashville's own talented makers and need-

knowers. We are continuing to hold Make-a-thon events and are very excited to see what these new projects have in store for the future of human-centered design and assistive technology.

If you want to learn more or get involved, you can visit our Facebook page. Simply search Facebook for "Tikkun Olam Makers: Vanderbilt."

Blake Hanan is a passionate biomedical engineering student and an undergraduate researcher at Vanderbilt University School of Medicine. Blake is also the community organizer and finance and fundraising chair for Tikkun Olam: Vanderbilt. ■



Team Zion designed an adaptive chair for a young rugby player.

Disability Rights TN New Helpline

You should know about LTSS Help TN, one of Disability Rights TN's newest programs.

LTSS stands for long-term services & supports. TennCare provides two Medicaid long-term services & supports programs: CHOICES and Employment and Community First CHOICES. LTSS Help TN provides information and support to applicants and/or members of these TennCare programs.

To learn more about how Disability Rights TN can help, contact 888-723-8193 or complete their form online <https://www.ltsshelptn.org/> for help.



Welcome, Cathlyn! Meet our New Director of Leadership Development

By Jolene Sharp, Chief Public Information Officer, TN Council on Developmental Disabilities

Cathlyn Kennedy Smith began her new role in February as the TN Council on Developmental Disabilities' first-ever Director of Leadership Development.

Cathlyn will be responsible for all activities under the Council's goal of leadership development. This includes:

- Partners in Policymaking®, our free leadership course for people with disabilities and family members of people with disabilities.
- The Leadership Academy for Excellence in Disability Services, a ground-breaking training for leaders of state disability services.
- The Council's Scholarship Fund, which helps people with disabilities and their family members attend educational opportunities and take on leadership roles in their communities.

"We are extremely fortunate to find someone with Cathlyn's skills, passion, and experience for this important position with the Council," said Executive Director Wanda Willis. "She has a track record for team building and will be an asset to our staff."

Cathlyn came to the Council from her previous position at the Department of Children's Services. She served as Executive Assistant and Tennessee's Commissioner for the Interstate Compact Commission for

Juveniles. She was also vice-chair of the Interstate Commission for Juveniles, which oversees the national member states. Cathlyn has two master's degrees, in public service management and in social work. She received the 2019 Governor's Award for Excellence.

Keep reading to hear directly from Cathlyn about her story and the things she's most excited about in her new role!

From the Director

I am very excited to start this new segment in my life in working for the Council on Developmental Disabilities. What really garnered my interest in this job was the keen focus on advocacy, education, and passion for people with disabilities.

I can recall from my early childhood becoming friends with several classmates with various physical and developmental disabilities. Growing up in a rural town in eastern Arkansas gave me the chance to interact in the classroom with many of these children every day. I have fond memories of their kindness and love towards me.

Service and protecting the rights of others is in my blood. My late grandfather, RBJ Campbelle, Jr., was a Nashville civil rights attorney during the Nashville sit-ins and civil rights movement. He continued his advocacy for youth and other vulnerable

Tennessee citizens throughout his career. My late mom, Jeanne Kennedy, served after retirement as a volunteer rape crises nurse in our rural community. Our town did not have a shelter, so growing up, I would often come home to find in my bed someone who needed a safe place to stay.

These early experiences became more important for me with the birth of my daughter, Tyler. The most dreaded words a new parent can hear are, "We think there is a problem with your child." Your heart stops for a moment, and instant fear and confusion flow over you. My daughter was born with a congenital, degenerative eye disease, and she also has hearing loss – what is considered Deafblind.

She has had more than eleven surgeries and takes multiple medications. I can relate to the lack of



Cathlyn Kennedy
Smith



Cat with her daughter, Tyler Samuel

resources, high medical bills, countless sleepless nights, and the feeling you are fighting an uphill battle, blindfolded, with your hands tied behind your back!

I had to advocate for Tyler from birth to ensure she had the right medical opportunities, access to services, and her right to a fully inclusive education. I did a lot of research on my own and learned by trial and error.

I became a single parent when she was five, and we moved to Tennessee. I had many teacher meetings and IEP planning sessions and advocated for her to be able to fully participate in activities. She did gymnastics, dance, horseback riding, theater, and music.

But, more importantly, I helped Tyler learn to advocate for herself. She was picked on in school and



Cat's daughter, Tyler, performs in many local theater productions

made to feel inferior because she was different. It was up to me and her "village" of extended family and friends to help her understand her value and purpose in this world.

More and more, Tyler believed in herself. She found her passion. She has accomplished so many things experts said she couldn't. She is a

college graduate (classically trained vocalist), working full-time, and living independently. But the thing I am most proud of is her ability to use her voice to make change.

In my new role, I am looking forward to continuing the great work that has been done with Partners in Policymaking® and other Council leadership programs. I will be looking to our current and future Partners graduates and leaders to help me learn what is most meaningful for an advocacy vision for 2020 and beyond.

I hope that my family story provides hope and encouragement for others in similar situations. Helping people with disabilities find and use their voices to make change is the greatest part of this work. Don't be surprised if I give you a call; we still have a lot of work to do! ■

Your Chance to Be Counted... *Continued from page 12*

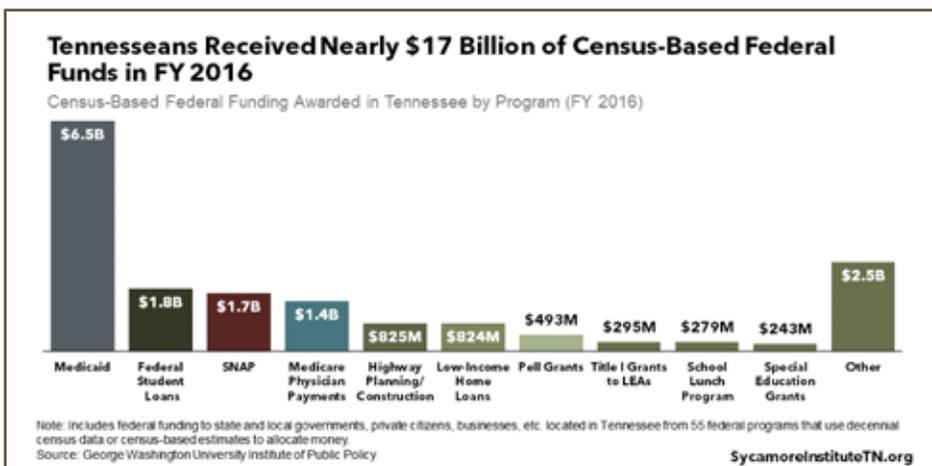
If you don't fill out the census using one of those three ways, a census worker may come to your house in May, June, or July to help you fill it out. All census workers will have a badge with their picture and information so you know they really work with the census.

Can my information be used against me?

No! The law says your census information can only be used for the census count. It won't be shared with law enforcement or immigration agencies or used in decisions about whether you qualify for benefits.

Will the census ask if I am disabled?

No. The census won't ask whether you have a disability. As we already mentioned, it's important for people with disabilities to be counted. The amount of money given to crucial programs is decided by how many people live in your city, county, and state. ■



Where Can I Learn More?

TheArc.org/census

Ndrn.org/issues/census-2020

DisabilityCounts2020.org

Official national census office:

1-800-923-8282

2020census.gov

What You Need to Know about TN's Early Intervention System

By Lauren LeGate, Public Information Officer, Department of Intellectual and Developmental Disabilities

As we welcome the fresh air and new growth of spring, the TN Department of Intellectual and Developmental Disabilities (DIDD) is also preparing for a big change. We are working to welcome the families and employees of the Tennessee Early Intervention System (TEIS).

Gov. Bill Lee issued an Executive Order last December that transfers TEIS from the Department of Education to DIDD. The move will be effective July 1.

DIDD has more than three decades of experience in providing and coordinating services for people with intellectual and developmental disabilities to live the lives they envision for themselves. Because of our shared mission with TEIS, we think the move will be a great fit for families and employees. We are truly excited! It's an opportunity for our dedicated and knowl-

edgeable staff to improve the lives of more people in Tennessee.

TEIS is a voluntary program that provides services to children from, in some cases, the moment they are born until their third birthday. Children born prematurely, diagnosed with a disability, or who may have a developmental delay will be offered support and services through a therapy plan designed to meet their needs. They may receive one or a combination of therapies: developmental, occupational, speech, or physical therapy. Their plan will provide what it takes to help the child reach their goals.

TEIS is governed by Part C of the Individuals with Disabilities Education Act (IDEA) and is provided at no cost to the family. DIDD's Commissioner Brad Turner has firsthand knowledge of the important work that TEIS provides.

"Before I was commissioner, I was a parent of a daughter with both intellectual and developmental disabilities. The support she received through the program and the guidance that was given to me and my wife changed our outlook," Commissioner Turner said. "The mission of this program is personal to me, and we will do everything we can to set up all children for success."

As you might imagine, shifting services for thousands of children and hundreds of employees is a big job. In the months since the announcement, DIDD staff members have been busy getting to know the daily operations of TEIS. Most importantly, they have been learning how they can make positive changes that will help staff members. Commissioner Turner and members of his executive team are using this time to visit TEIS offices across the state. They are asking questions about how to improve support to families and providing information about what will change when July gets here.

We are busy behind the scenes so that once the change happens, our families will not be affected. The services TEIS provides are not changing – just the department that coordinates the services. We are hopeful we can improve the great work being provided. We think the children enrolled in TEIS will come to expect great things from DIDD staff and providers.



DIDD leadership has visited all nine TEIS regional teams, including the South Central staff pictured here, to hear their passion, feedback, and insights.

Around the same time DIDD is welcoming TEIS, another exciting program will be kicking off. The Katie Beckett Waiver Program is also expected to begin in 2020. This new program will provide support for children under the age of 18 who have disabilities or serious medical needs. Not all children who receive TEIS services will be eligible for the Katie Beckett Program. However, we hope these two programs will allow children and families to find a home within our department as they grow older and work to meet their goals.

As the transition of TEIS gets closer, we look forward to hearing from families who have been a part of the TEIS program. Sharing your personal experiences about the benefits and the challenges will

help future families that we welcome into the program. In addition to the dedicated staff already working on behalf of TEIS, the Assistant Commissioner of TEIS, Dr. Gabrielle Madison, and myself have been brought on board. We will be working to increase awareness about the program and support those who work with children and families.

When news of the move made its way through our department, long-time staff members who remember when DIDD played a role in early intervention were thrilled. They have seen the difference the program can make in the lives of babies. DIDD is invested in helping each person live their most fulfilling life. We are very excited about this chance to welcome babies and toddlers that we can sup-

port to blossom into their best selves.

For more information on the TEIS transition and DIDD, please visit our website; <https://www.tn.gov/didd/teis>.

Lauren LeGate is the Public Information Officer for the Department of Intellectual and Developmental Disabilities. Lauren is a native of East Tennessee and a graduate of the University of Tennessee. She will be primarily focusing on the Tennessee Early Intervention



Lauren LeGate

System (TEIS) program. Lauren comes to DIDD with 16 years of TV news experience and is looking forward to sharing the great stories happening within TEIS. ■

Council Member View... *Continued from page 13*



Governor Bill Lee offered opening remarks for the State of Disability Services in Tennessee program.

These meetings give those of us with disabilities a rare moment to inform our legislators about areas state services can be improved or where services are lacking. The importance of such meetings cannot be overstated. They “put a name and a face” to our disability for lawmakers to recall when deciding whether or not to sponsor a particular bill.

Disability does not discriminate. Every person is in some way affected, either directly or indirectly, by physical, developmental, and/or intellectual disabilities. I have been blind since birth and am acutely aware of the obstacles that daily confront the visually impaired. However, because I attended Disability Day on the Hill, I now have more insight into and knowledge

about services that benefit other disabled persons.

I left the 2020 Disability Day on the Hill feeling heartened. Our lawmakers are more aware than ever of the needs of the disability community and of how laws may be changed and funding made available to address these pressing concerns.

Sarah Cripps was appointed to the Council on Developmental Disabilities by Governor Bill Lee in 2019. She is a general practice attorney and family mediator in Smithville and is specially trained in domestic violence issues.

She is married to Mack Garner, loves to travel and eat dessert first, and promises never to cook you dinner. ■



Sara Cripps

Tennessee Council on Developmental Disabilities

Davy Crockett Tower, 1st Floor
500 James Robertson Parkway
Nashville, TN 37243
Return service requested

PRESORTED
FIRST-CLASS MAIL
U.S. POSTAGE PAID
NASHVILLE, TN
PERMIT NO. 963

MEMBERSHIP AND STAFF

COUNCIL CHAIRPERSON

Tecia Puckett Pryor, Chair

COUNCIL MEMBERS

Alison Bynum, Smyrna
Jody Cheek, Johnson City
Roddey Coe, Ooltewah
Jennifer Coleman, Paris
Sarah Cripps, Smithville
Ryan Durham, Lawrenceburg
Tatum Fowler, Knoxville
Lesley Guilaran, Jackson
Alicia Hall, Cordova
Chrissy Hood, Pulaski
Clancey Hopper, Lebanon
Lisa Johnson, Greeneville
Jean-Marie Lawrence, Chattanooga
Craig Lemak, Knoxville
Linda Monterroso, Memphis
Brigham Scallion, Bells
Gina Summer, Jackson
Karen West, Gallatin
Brent Wiles, Nashville
Martez Williams, Nashville

STATE AGENCY REPRESENTATIVES

Commissioner Brad Turner
Department of Intellectual and
Developmental Disabilities
Commissioner Penny Schwinn,
Department of Education
Assistant Commissioner
Mandy Johnson,
Department of Human Services,
Vocational Rehabilitation Services
Commissioner Marie Williams,
Department of Mental Health and
Substance Abuse Services
Director Morgan McDonald,
MD FAAP FACP,
Division of Family Health and Wellness,
Department of Health
Assistant Commissioner
Patti Killingsworth,
Bureau of TennCare
Executive Director Richard Kennedy,
Commission on Children and Youth
Executive Director Ralph Perrey,
Tennessee Housing Development Agency
Executive Director Jim Shulman,
Commission on Aging and Disability

UNIVERSITY CENTERS FOR EXCELLENCE REPRESENTATIVES

Elise McMillan, J.D., Co-Director,
Vanderbilt Kennedy Center for Excellence
in Developmental Disabilities

Bruce L. Keisling, Ph.D., Executive Director,
UT Center for Developmental Disabilities

PROTECTION & ADVOCACY

Lisa Primm, Executive Director,
Disability Rights Tennessee

LOCAL NONGOVERNMENTAL AGENCY

Sarah Kassas

COUNCIL STAFF

Wanda Willis, Executive Director
Lynette Porter, Deputy Director
Cathlyn Smith,
Director of Leadership Development
Ashley Edwards, Executive Assistant
JoEllen Fowler, Administrative Assistant
Mildred Sparkman,
Administrative Secretary
Alicia Cone,
Director of Programs Operation
Emma Shouse Garton,
Public Information Specialist
Lauren Percy, Director of Public Policy
Jolene Sharp,
Chief Public Information Officer